

Chronicle of a death delayed: the taboo of death and non-scientific limits of Science

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Abstract

This report, presented as a case study, follows the eight days between internment for implantation of a pacemaker and the passing of a 92 year old person, with a history of hypertension and diabetes mellitus and at an advanced stage of Alzheimer's disease, characterized by complete loss of long and short term memory and an overall diagnosis of dementia with total incapacity for comprehension of his or her own hospital context. This is a report from the viewpoint of an observer with affective ties to the focus subject and with academic activities outside the area of medicine.

Keywords: Attitude to death. Fatal outcome. Terminal care. Alzheimer disease. Dementia. Morals-Pleasure-Pain principle. Euthanasia.

Resumo

Crônica de uma morte adiada: o tabu da morte e os limites não científicos da ciência

Este relato, apresentado como estudo de caso, acompanha os oito dias que transcorreram entre a internação para a implantação de um marca-passo e o falecimento de um sujeito de 92 anos, com histórico de hipertensão, diabetes melito e em estágio avançado de Alzheimer, caracterizado por completa perda das memórias de longo e curto prazos e por quadro geral de demência, com total incapacidade de compreensão de sua situação no contexto hospitalar. Trata-se de relato de caráter subjetivo, realizado por um observador com vínculos afetivos com o sujeito objeto da observação e com atuação acadêmica em área estranha à medicina.

Palavras-chave: Atitude frente à morte. Evolução fatal. Assistência terminal. Doença de Alzheimer. Demência. Moralidade- Princípio do Prazer-Desprazer. Eutanásia.

Resumen

Crónica de una muerte anunciada: el tabú de la muerte y los límites no científicos de la ciencia

Este relato, presentado como estudio de caso, acompaña los ocho días que transcurrieron entre la internación para la implantación de un marcapaso y el fallecimiento de un sujeto de noventa y dos años, con un historial de hipertensión, diabetes *mellitus* y un estadio avanzado de Alzheimer, caracterizado por una completa pérdida de memoria de largo y corto plazo y por un cuadro general de demencia con total incapacidad de comprensión de su situación en el contexto hospitalario. Se trata de un relato realizado a partir del punto de vista subjetivo de un observador con vínculos afectivos con el sujeto objeto de observación y con una actuación académica en un área ajena a la Medicina.

Palabras-clave: Actitud frente a la muerte. Resultado fatal. Cuidado terminal. Enfermedad de Alzheimer. Demencia. Principios morales- Principio de dolor-Placer. Eutanasia.

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Declara não haver conflito de interesse.

What is reported here is the subjective experience of the death of a relative for whom one is responsible, in a hospital setting context that provides state of the art medical technology and access to the most advanced scientific knowledge; and in a religious, moral and institutional context in which beliefs, customs and legal practices regulate and standardise the experience of death in our society. The author is an architect and urban planner, and currently teaches at the Faculty of Architecture and Urbanism at the Federal University of Rio de Janeiro (FAU-UFRJ). His academic background also includes a master's degree in public health from the National School of Public Health Sérgio Arouca of the Oswaldo Cruz Foundation (Ensp-Fiocruz), as well as two doctorates: one in Psychology from the Catholic University of Rio de Janeiro (PUC-Rio) and another one in Urban Planning, from the Post Graduation Program in Urban Planning (ProUrb) of the FAU-UFRJ.

Such an academic background could "a priori" disqualify this report as a scientific work, given the distance between the professional qualifications of the author and the areas of knowledge in which the subject matters are investigated. In addition, the family relationship and affection between the author and the subject who is the object of the observation could also harm the methodological distance that is necessary for scientific research. On the other hand, it is unreasonable to dismiss the value of the direct report of a researcher trained in scientific practice who witnessed, as a family member, the end of the life of a loved one in a hospital. I am presenting this report in the hope that it will contribute to the thinking of health professionals working in hospitals, be it in intensive care or not.

The thinking acquires extraordinary relevance when one faces the clear moral conflict created between the obscuring taboo surrounding the idea of death in Western societies^{1,2} and recent rules issued by the Federal Council of Medicine (CFM)^{3,4}. These rules, through different legal processes, start to admit that practitioners abide by previous patient's decision about suspension of curative treatment and administration of palliative care, where death is imminent and there is no expectation of cure, and where the extension of life would only increase the suffering of the patient.

The framework of hospitalisation

The hospitalisation occurred on December 23, 2014, in the hospital of a capital city situated about

2000 km from where I live. We were, my daughter and I, travelling to this city, where we would spend Christmas with my dad, who is the object of this report. We were driving and were unreachable by phone.

When we arrived at night he was already a post-operative patient in the intensive care unit (ICU). Malaise, loss of appetite and prostration were the symptoms that led the person who accompanied him to seek medical help. He had a slow heart rate of 30 beats per minute, what characterised bradycardia. The medical advice consisted of immediate hospitalisation for pacemaker implantation.

The patient entry form added to the medical history the systematic use of propranolol, which had been suspended two days before by the assistant doctor. The physical examination data confirm 33 heart beats per minute. The diagnosis is confirmed as symptomatic bradycardia and second degree atrioventricular block (AVB). The forwarding is for the use of a temporary pacemaker. The result of the examination, recorded as code 1500, is of congestive heart failure.

The Preanesthetic assessment indicates hypertension and arrhythmia, in the cardio-circulatory field, and dementia, in the neurological field. The medical evaluation notes the impossibility of assessing the emotional state of the patient, due to a communication barrier caused by physical and mental limitations. The surgery took place between 5pm and 6 pm that day. The first post-operative report, already on the 24th of December, evaluates the physiotherapeutic cardiorespiratory condition. Among other data, the report qualifies the patient's condition as alert, confused and uncooperative.

This morning, I could establish the first contact with my father. He had already been extubated but he could not articulate words and emitted sounds only. Part of this difficulty was the result of dementia, as for more than a year he had been using his voice more to express emotions than to formulate intelligible concepts. Another reason, according to a doctor who was present, was due to his throat being hurt by intubation.

He was awake, confused and extremely agitated. He was tied into the bed with bandages around his wrists and ankles, and made constant efforts to free himself from the bandages. He spoke, or emitted sounds in fluent speech, but paragrammatical and uninterrupted, without pauses or syntactic alternations. Several devices were connected to his body: chest electrodes, sensor on a finger, urethral

probe, two nasal probes, intravenous probe, besides the oxygen mask.

His intense discomfort and his complete lack of understanding of his own situation were evident. The call for help, relief and to be freed from the bandages was unmistakable. It was expressed by the effort to get rid of the bandages, the sounds he emitted and his facial expressions, indicating a state that I can only define as despair.

The very unusual aspect of the situation, looking back in time, was caused by the dementia. In my personal experience, the main cause of the discomfort came from the feeling of helplessness resulting from the complete inability to offer to my father any form of understanding or justification for what was happening to him. And it seemed clear that, for him, the main cause of the discomfort was the lack of understanding about his situation.

According to the Hospital records, entry to the Intensive Care Unit (ICU) occurred at 18h57 on December 23 and the move to a single room at 18h29 on 26 December. During this period we were allowed to visit him twice a day, for a few minutes, and the clinical status that we could observe on all visits remained as I have described. I will now transcribe excerpts from medical records, with the notes and prescriptions that seem most relevant for understanding the evolution of my father's medical condition during the period in which he remained in the ICU:

23/12

- 18h57: prescription of Precedex [dexmedetomidine hydrochloride - an analgesic and sedative adrenergic alpha 2 agonist for patients in intensive care].
- 20h21: Precedex.

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- 8h27 [doctor's notes]: *agitated patient, receiving 10 mL / hr Precedex ; I prescribe Haldol [antipsychotic used against psychoses and schizophrenia and as antidystonic for nausea and vomiting].*
- 8h45: *extubation saturating 89% - 91%.*
- 9h02 [notes from the assistant doctor]: *patient with hypertensive and ischemic cardiopathy , type 2 diabetes, senile dementia, complete AV block [atrioventricular block] , temporary pacemaker implantation and, later, definitive, agitated, (...) try extubation even in non-ideal condi-*

tions; I prescribe quetiapine [antipsychotic] for chronic use.

- 9h25: *Request of rectal swab [collection of sample].*
- 10h40 [note of the doctor on call]: *patient has been sedated with Precedex 10 mL / hr; I prescribe Haldol SN (if necessary) , FC (heart beats per minute) 64 .*
- 12h31 [note of the doctor] *I prescribe physiotherapy*
- 13h01 [Physiotherapist notes]: *patient (...) awake and very agitated, does not respond to commands; I perform extubation accompanied by the MP (pacemaker), FC (heart beats per minute) 89, saturation 92%.*
- 13h59 [doctor's notes]: *Precedex 10 mL / hr, eye opening to painful stimuli, does not obey to commands, periods of agitation, I believe this should be the basic neurological status of patient , restarting Seroquel [quetiapine - antipsychotic] and Exelon [rivastigmine - dementia of the Alzheimer's type and Parkinson], I let Haldol as back up help, I reduce Precedex.*
- 16h31 [dietitian's notes]: *patient woke up and is very agitated, unable to VO [oral feeding].*
- 16h36 [doctor's notes]: *patient is very agitated, tries to leave the bed, confused, Precedex reduced in the afternoon, haloperidol now, I increase Precedex, without conditions for VO diet (oral feeding), periods of sleepiness and agitation; I prescribe SNE [nasogastric tube].*
- 18h07 [nursing staff's note]: *patient with psychomotor agitation, I made an unsuccessful attempt to pass SNE , (...) on-call doctor advises to increase intravenous sedation with the application of one ampoule of Haldol.*
- 18h40 [nursing staff's note]: *agitated patient.*
- 22h21 [nursing staff's notes]: *SNE passed, with positive auscultation; I request RX (X-ray) for confirmation.*
- 22h21 [anotações da enfermagem]: *passada SNE, com ausculta positiva; solicito RX para confirmação.*

25/12

- 02h54 [nursing staff's notes]: *subjective: without conditions of evaluation, disquiet patient with continuous sedation (RASS +2) [Richmond agitation and sedation scale], inserted tube SCD (right subclavian) with infusion [valved catheter with*

- access via the right subclavian vein] *Precedex 20 mL /hr, SGF (glucose serum) 40 mL /hr, FC 79 bpm. (heart beat per minute)*
- 10h17 [physiotherapist notes] (...) *agitated and unresponsive patient (...).*
 - 10h17 [anotações do fisioterapeuta]: (...) *paciente agitado e não responsivo (...).*
 - 11h24 [Assistant doctor's notes]: *restless patient, confused, a lot of pus, FC 70 bpm. (heart beat per minute)*
 - 11h28 [note of the doctor on call] *I prescribe Zyprexa [olanzapine - antipsychotic].*
 - 17h02 [physiotherapist notes] (...) *agitated and unresponsive patient (...).*
 - 18h06 [nursing staff's notes]: *patient restless in bed, the assistant doctor passes SNE (nasogastric probe), control RX (X-ray) done, started diet 38 mL / hr, inserted tube SCD with Precedex 20 mL / hr, SGF 40 mL / hr. (glucose serum)*
 - 21h35 [notes of the doctor on-call]: *confused, agitated, eupneic; FC 60 bpm (heart beat per minute); Haldol now.*
 - 22h17 [nursing staff's note]: *agitated, confused, spontaneous eye opening, breathing spontaneously through a nasal catheter 2 L / min O₂, valved introducer (...) infusing Precedex 20 mL / hr, SGF 40 mL / hr .*

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- 8h29 [notes of the Assistant Doctor]: *same clinical status, RC 60 COM [coronary flow reserve], increased dose of quetiapine; discharge from the ICU.*
- 12h44 [physiotherapist notes]: *patient (...) agitated and unresponsive (...).*
- 15h38 [physiotherapist notes] (...) *agitated and unresponsive (...).*
- 18h29: *ICU discharge; [Non ICU Nursing staff's notes]: I received patient from the ICU (...); Previous: Alzheimer's, hypertension [high blood pressure], DM [diabetes mellitus], hearing loss; patient is accompanied by his son ; subjective: impaired; given Haldol for psychomotor agitation; objective: very agitated, confused (...) while maintaining mechanical restraint [bandages] to prevent withdrawal of the SNE [nasal probe].*

What seems to stand out in these notes is the medical effort to control, through the use of drugs that could fall under the general category of an-

tipsychotics, signs of anxiety and discomfort that appeared in the form of restlessness, confusion and agitation, and that were attributed to dementia caused by Alzheimer . Subsequently, it was found that these efforts were, in fact, contributing to produce such a clinical picture when it was diagnosed that the effects of saturation from Haldol correspond to the very same symptoms that the medicament is intended to control.

The discharge from the ICU was negotiated with the Assistant Doctor. My father didn't sleep during the whole 72 hours that he remained in the ICU. He also stayed in a constant state of agitation. The arid and hectic environment of the ICU, the constant manipulation of the body, the absence of the family, that could only stay for a few minutes a day in two quick visits, seemed to have left obvious marks on his psychological state. His high degree of stress was noticeable, demonstrated by the unrest, the unvarying rhythm of the confused and aphasic speech and his facial expressions.

The enormous effort that my father made constantly to free himself from the bandages began to produce strong alterations in his heart rate. In view of these changes it became increasingly evident that the pacemaker was not able to produce the desired effects. On the one hand, there was a subjugated body, an object open to technical manipulation; on the other, a demented psychic subject who, in the absence of an understanding of his situation, resists the technical project to which he is subjected.

It is, as a matter of fact, a techno-scientific project that is provided not only with scientific knowledge but also with mechanical, electronic, computing, and chemical means necessary for the attainment of its objectives which, due to ethical principles, enable the maintenance of life. The venous access, in particular, opens the body to chemical manipulation, turning the patient into a docile object for the medical interpretation and at their discretion, ensuring the technical feasibility of this project. Everything is arranged in a functional composition, planned according to the demands of medical technology and expressed by an aesthetics of cleanliness and purity.

The body-object is an object that is obliging to the medical manipulation. Subdued as it is by the chemical venous access and by the bandages , it is kept in a somatic state of life by feeding , breathing and hydration tubes and isolated from the environment by the excluding probes. Something, however, seems to fail. On the uniqueness of a demented man, the generality of the technical project does not meet the expected

response. It fails, as all rationality fails against irrationality. And, against the latter, reason can only be imposed in a single way: force. The ties that bind the subject to bed are the unequivocal testimony.

The period in a hospital single room went from 18h30 on 26 December to 10h30 on the 30th, when the passing away took place. This period is divided into two parts. The first goes until 1h40 on the 27th, when the on-call team decided to readmit the patient in the ICU on the evidence, noted in medical records, of malfunctioning of the pacemaker and the neurological status of the patient, marked by agitation.

I was informed at 02h00 by a phone call from my daughter, who was with my father that night. She reported that after the last infusion of Haldol, there was a peak of agitation, followed by strong variations in the heart rate. The doctor, at the request of the nurses, had decided to readmit the patient to the ICU. I instruct my daughter to deny permission, and ask the doctor to wait for my arrival, which happens 30 minutes later.

We talked, the doctor and I, for about 30 minutes. He was a young man whose training, as it transpired during the talk, turned out to be much broader and sophisticated than the basic scope of technical training in medicine. I can not retrieve from memory the exact content of the conversation, and I had not made notes on this occasion, but I remember a phrase used by the professional at some point: "I do not claim to be God."

I clearly remember how, at that moment, the comments of Sigmund Freud in "Civilisation and its Discontents" occurred to me, on the ideal concept of omnipotence and omniscience projected by men on their gods: *Man has, as it were, become a kind of prosthetic God. When he puts on all his auxiliary organs, he is truly magnificent; but those organs have not grown on him and they still give him much trouble at times*⁵.

Indeed, I found myself faced with a difficulty: it appeared, at the time, that my father would not leave that hospital alive, even though the ICU environment would allow life to be maintained virtually indefinitely. A situation was established where there would be no natural death. From that point, we understand - I and the hospital doctor - that the death of my father was a matter of decision-making.

I did not hesitate to take it after a brief conversation with my daughter. But it turns out that the decision-making power in the hospital environment is shared with many actors, all of them subjected to

different belief systems and pressured by moral values and legal provisions that consider life a value of clearly transcendental nature. What took place, from that moment on, was a conflict between these belief systems.

In a hospital setting like that one, which has scientific knowledge and advanced technical resources, somatic life is, in fact, far from being lost. To each "abnormality" of vital functions, the doctor will give the technically correct response. Considering the medical ethics and moral values involved in the matter, the correct perspective of the subject doctor would be to maintain the biological life of the object body manipulated by him. But is that the right thing from the point of view of the subject patient? Is it correct not to consider the patient able to decide on what is right? Is it correct to interpret the irrational resistance of the insane subject as an inability of deciding about your own life?

Finally, could it be that the correct thing from a technical point of view is not correct from the point of view of the recipient? Who does the decision benefit? The subject doctor who manipulates the body or the body object being technically manipulated?

Now I present excerpts from the medical records containing the description of the clinical events from the morning of December 27 that demonstrate the magnitude of distress of this situation, both for my father, my daughter and I as for the professionals who assisted my father:

27/12

- 1h35 [hospitalist's notes]: *I was called because of clinical picture of psychomotor agitation . S - unable to proper conversation, agitated, excessive perspiration, hypertensive. Spastic, signs of saturation with haloperidol (cogwheel rigidity -akathisia). No specific complaints. Companion relates what happened [the elevation of psychomotor agitation after the use of haloperidol and Seroquel. (...) FC [heart rate] varying between 45 and 86 bpm. (...) A - saturation with haloperidol. Pacemaker dysfunction. New infection without a defined focus. Clinical deterioration to be clarified. C - I suspend haloperidol, I prescribe biperiden ; I request RXT (X-ray) + ECG + labs. + GA.(Arterial Blood Gas)*
- 1h42 : *ECG: sinus bradycardia without MP (pacemaker) input signals, FC ~ 40 bpm (...).*
- 02h00 : *I contact the on-call cardio doctor, show ECG: sinus rhythm, FC (heart rate) ~ 40-50 bpm.*

Nothing to do at the moment. Patient is calm and sleepy after biperiden (...).

- *02h38 : remains ventilatory effort, tachypnea, (...) bradycardic and hypoxic (improves with Hudson mask 10 L / min); risk of progression to respiratory failure; I request ICU bed; I wait for relative- son (as requested by the patient's granddaughter).*
- *03h24 : family [son of the patient] requests that patient is not sent to the ICU. He asks to restrict therapeutic measures and prioritise the patient's comfort. I accept the request and suspend ICU bed.*

Despite the notes, we find out that the request had been met only partially because of the intense relay of different professionals who, supported by the discretionary power granted to the medical staff in the hospital, intervene according to their own beliefs and values. My father did not return to the ICU, but the therapeutic measures were maintained and intensified by doctors and nurses who took the place of the doctor hospitalist, author of cited notes from medical records .

However, there could no longer be any doubt: the axis of the therapeutic strategy - the implementation of the pacemaker - had failed. There was no reasonable expectation of cure or improvement of the symptoms that led to hospitalisation. From now on, it was a matter that escaped the field of healing medical technique and was driven exclusively by moral values and the fear imposed by legal provisions.

Then began the second part of that period, starting with the ICU discharge. From that moment on, the issues that emerged were the assimilation of these facts in the affective context of the relatives and of the resistance to the therapeutic obstinacy in the hospital context, in order to avoid or minimise unproductive and sterile suffering.

The framework of the Death

The framework was not clear to me at that time because I only had access to medical records after the death of my father. The medical discourse is always encrypted, never clear or objective. The verb "wait" governs the discourse. Of all the doctors and nurses with whom I had the opportunity to dialogue, that hospitalist was the only one who did not hesitate to provide all requested clarifications and take responsibility for defined predictions. The

death was a matter of time - time that inherently depended on the therapeutic choices adopted.

The decision to veto the return to the ICU did not happen, in any way, based on the analyses and reflections that I could do only later but on the indisputable evidence of the therapy irrationality and absolute lack of intelligible purpose in the proposed therapeutic strategy . The phrase most used by the therapy team was: "We have to wait." But arguably the patient's time meant only suffering.

Despite the change on the prescribed drugs, my father spent the rest of the early hours of the 27th and until shortly after dawn, awake, confused, agitated and tied to the bed. But now he is talking a little or just whispering. He keeps his eyes open and staring at the ceiling. My daughter and I alternate, offering our hand, which he holds strongly . His hand conveys the strong agitation that animates him: always in movement, often digging his nails into our hands and hurting them.

At around 8h00, we received a visit from the assistant doctor. I am told that we must wait. Faced with this situation, I requested the presence of an expert in suffering. The following are notes from the treating physician in the medical record:

27/12

- *8h06 : at the moment, quiet (...) I suspend haloperidol. Combined with comfort measures. I request neurological evaluation focusing on measures to control psychomotor agitation.*

At about 09h00, the nurse shows up in order to do the hygiene of the patient. Coincidentally, this was the first time my father slept in the post-operative ICU. He had no sleep for more than 90 hours, so I did not allow the nurse to awaken him. They explained to me that this was the routine of the hospital, and if hygiene was not conducted at that time, there would be problems with the next shift team, which did not have this routine included in their obligations. I kept the restriction.

Near 10 am, we received a visit from the neurologist who asks us to reconsider the readmittance to the ICU. I question the objectives of the measure and do not get a satisfactory answer. I keep the veto. The following are the notes of the neurologist in the medical record:

27/12

- *10h57: evaluation of akathisia: patient had been on haloperidol, chlorpromazine and quetiapine.*

He started, during the first hours of this day, with severe psychomotor agitation. Managed by MH (hospitalist doctor) and the MA (assistant doctor), who requested neurological monitoring. I talk to his son, who confirms the story of worsening of symptoms after use of neuroleptics and insists on the management of comfort, vetoing the admission of the patient to the ICU. On examination: tax (axillary temperature) 37.5; lung snoring; akathisia; incomprehensible language; move all four limbs; normal pupils. Conduct: I talk with family members and explain the case; I suspend antidopaminergic drugs. Complement: I let amantadine and diazepam; 5 mg diazepam IV now.

We are in the early afternoon of the 27th. We observed that stools begin to overflow from diapers. Not to create problems with the nursing staff, we decided, my daughter and I, to change the diapers ourselves. I turned my father on the bed and as I held him my daughter changed his diaper and cleaned the accumulated faeces. But the continuous tube feeding had produced large amounts of faeces not eliminated yet and when we moved his body to put the new diapers, my father started an intensive process of evacuation, which overflowed for most of the bed.

My daughter asks for help from the nurses, and we are helped by two technicians. The manoeuvres necessary to solve the situation, which involved the complete replacement of bed sheets and covers and required moving the patient, who resists with vigorous efforts, causing immediate and strong variations in his heart rate and the return to a visible state of restlessness.

The new medication managed to produce partial sedation, alternating moments of sleep with moments of awakesness and intense agitation. Sleep is also very disturbed. Constant spasms with trembling limb movement, speech moments with a few scattered sounds and intense facial expressions. Nursing staff continues to monitor vital signs and to provide the serum infusion, food and medicine, routinely and/or in response to changes in vital signs, particularly of insulin.

This clinical picture does not change, and it will extend until the 29th, with noticeable steady deterioration of vital signs and the loss of strength and range of body movements and speech. It was visible that the life of my father was fading, wilting like droplets expelled from a dropper.

The dawn of the 29th was one of the hardest. The notes in the medical record are clarifying :

29/12

- 5h23 [nursing staff's notes]: subjective: impaired, administering diazepam 2 + Phenergan 1 overnight for psychomotor agitation. Objective: sleepy, very agitated for periods, confused (...) breathing with O₂ at 15 L / min by Hudson mask. attempted to keep mask with nasal cannula, but without success. Desaturated (...).
- 11h19 [notes of the neurologist]: evaluation of akathisia; patient in Venturi mask, with a slight respiratory effort. Family expressed desire not to initiate advanced life support measures, requests sedation for comfort; afebrile; CD (conduct): I prescribe morphine, if necessary; I have a long talk with family members; other settings left to the Assistant Doctor's discretion.
- 17h30 [nursing staff's notes]: patient is MEG (general malaise) presenting ventilatory effort with O₂ MH at 15 L / min; I administered morphine, according to medical prescription.
- 17h59: Patient presented improvement of ventilatory effort after aspiration of VAS (upper airway) and administration of fixed medication. Morphine not administered. Keep SN.

The question of the use of morphine is most probably the most revealing of the moral aspects involved at this time. Like any opiate or similar recreational drug, morphine combines a powerful anaesthetic and sedative capacity with a natural ability to produce pleasure and even euphoria. On the other hand, it causes respiratory depression and, in a difficult framework of breathing effort like this one, it tends to hasten death. Furthermore, morphine causes dependence syndrome, which was obviously irrelevant in the case of my father.

On one hand, sedation and pleasure; on the other hand, reduction of lifetime. The question arises: what life? One that is subjected to this level of chemical intervention, as seen upon reading the chart, only to become minimally viable and endurable, as in the case of sedation? Is it for a few more hours of this kind of life the reason why the pleasure of morphine is denied?

Pleasure is, in fact, frowned upon in our culture. Since Eve's apple, the pleasure is related to a significant part of the taboos or sins standardised by religions. Pleasure is associated with sexuality and consequently lasciviousness and moral degeneration. Degeneration is paid with time of life.

The association between use of drugs and death is known. The price of pleasure is, in our culture, paid with the currency "life". It is not surprising

that, in the hospital environment, where everything is arranged according to the principles of life support, and where all efforts are locked in a close fight against death, the use of morphine is always something measured and moderated. Indeed, in our culture, the hospital is not a good place to die. There, a good death is not possible⁶.

At 17h59, a nurse, almost exulting over the improvement of the patient, registers in the medical records that she did not apply the prescribed morphine. At 10h00 in the next day my father died. Sixteen hours of pleasure were denied to him. In exchange for what? A few hours more of what? Between the medical decision to perform surgical procedure for pacemaker implantation in a 92 year old patient, demented and with the medical history described here, and the death, 161 hours have passed - 161 hours strapped to a hospital bed, with all the discomforts of a post heart surgery, and more than 80% of that time in a state described as "awake, restless, confused, with akathisia" and constantly subjected to all kinds of manipulation, as seen in the notes about his clinical picture:

30/12

- 9h54 [nursing staff's notes]: *subjective: impaired. Objective: sleepy, MEG (general malaise), damp and pale mucous membranes, ventilated with O₂ at 15 L / min with Hudson mask; difficulty breathing, sat. 88% gasping. SNE (nasal probe) 75 mL/ hr with good acceptance. Keeps tube introducer in SCD (right subclavian) infusing SRT PMV (to keep veins) without signs of inflammation in the insert. gauze dressing and micro-*

pore surgical tape. Flabby abdomen, RHA (bowel sounds) + SCE (left subclavian) with hematoma. Extremities heated and perfused. Maintains mechanical restraint to prevent withdrawal of the SNE. Use of diapers. Spontaneous diuresis.

- 10h30 [notes of medical hospitalist]: *I am called by the nurse to register patient's PNR (Patient who can not be reanimated). Death found at 10h30.*

Final considerations

Death is taboo in our culture⁷. It escapes the scope of what we can deal with rationally. The limit of the medical science, or of those who practice it, is the struggle for life. In all the conversations I had with doctors in hospitals, death was an avoided subject, bypassed, muted. Outside that environment, I was able to talk with experienced physicians, who mentioned rare cases of a more pious attitude towards death.

In general, however, the hospital environment, whilst providing complete support for life, allows the solitary death and helplessness without any assistance⁸. Regardless to occur within a few hours or extended for days, weeks or even months, everything is done to delay it and very little to make it a good experience⁹. Faced with the insurmountable resistance of professionals to discuss the matter, we had to accept and facilitate this existential imperative - death -, we were allowed to do little besides untying my father in the minutes preceding his death.


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